

Free Executive Summary



Approaching Death: Improving Care at the End of Life

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Committee on Care at the End of Life, Institute of
Medicine

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When the end of life makes its inevitable appearance, people should be able to expect reliable, humane, and effective caregiving. Yet too many dying people suffer unnecessarily. While an "overtreated" dying is feared, untreated pain or emotional abandonment are equally frightening. Approaching Death reflects a wide-ranging effort to understand what we know about care at the end of life, what we have yet to learn, and what we know but do not adequately apply. It seeks to build understanding of what constitutes good care for the dying and offers recommendations to decisionmakers that address specific barriers to achieving good care. This volume offers a profile of when, where, and how Americans die. It examines the dimensions of caring at the end of life: Determining diagnosis and prognosis and communicating these to patient and family. Establishing clinical and personal goals. Matching physical, psychological, spiritual, and practical care strategies to the patient's values and circumstances. Approaching Death considers the dying experience in hospitals, nursing homes, and other settings and the role of interdisciplinary teams and managed care. It offers perspectives on quality measurement and improvement, the role of practice guidelines, cost concerns, and legal issues such as assisted suicide. The book proposes how health professionals can become better prepared to care well for those who are dying and to understand that these are not patients for whom "nothing can be done."

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Summary

Dying is at once a fact of life and a profound mystery. Death comes to all, yet each person experiences it in ways that are only partly accessible to the physician or family member, the philosopher or researcher. In principle, humane care for those approaching death is a social obligation as well as a personal offering from those directly involved. In reality, both society and individuals often fall short of what is reasonably—if not simply—achievable. As a result, people have come both to fear a technologically over-treated and protracted death and to dread the prospect of abandonment and untreated physical and emotional distress.

A humane care system is one that people can trust to serve them well as they die, even if their needs and beliefs call for a departure from typical practices. It honors and protects those who are dying, conveys by word and action that dignity resides in people—not physical attributes—and helps people to preserve their integrity while coping with unavoidable physical insults and losses. Such reliably excellent and respectful care at the end of life is an attainable goal, but realizing it will require many changes in attitudes, policies, and actions. System changes—not just changes in individual beliefs and actions—are necessary.

A number of developments suggest that the time is right for action at all levels to improve care at the end of life and to assure people that they will be neither abandoned nor maltreated as they approach death. This Institute of Medicine report is intended to support such action by strengthening popular and professional understanding of what constitutes good care at the end of life and by encouraging a wider societal commitment to caring

well for people as they die. More specifically, it is intended to stimulate health professionals and managers, researchers, policymakers, funders of health care, and the public at large to develop more constructive perspectives on dying and death and to improve the practices and policies under their control. To these ends, this report stresses several themes.

- Too many dying people suffer from pain and other distress that clinicians could prevent or relieve with existing knowledge and therapies.
- Significant organizational, economic, legal, and educational impediments to good care can be identified and, in varying degrees, remedied.
- Important gaps in scientific knowledge about the end of life need serious attention from biomedical, social science, and health services researchers.
- Strengthening accountability for the quality of care at the end of life will require better data and tools for evaluating the outcomes important to patients and families.

CONTEXT AND TRENDS

In the United States, death at home in the care of family has been widely superseded by a technological, professional, and institutional process of treatment for the dying. That process—its benefits notwithstanding—often isolates the final stage of life from the rest of living. Likewise, the mobility of Americans quite literally puts distance between many younger and older family members. Many adults, even in middle age, have not lived with or cared for someone who was dying.

Because Americans, on average, live much longer now than they did at the end of the nineteenth century, a much larger proportion of the population dies at an advanced age. More than 70 percent of those who die each year are age 65 or over, and those who die in old age tend to die of different causes than those who die young. For both younger and older people, the major causes of death and the typical experience of dying differ from 100 years ago. The dying process today tends to be more extended, in part because medical treatments can manage pneumonia, infections, kidney failure, and other immediate causes of death that come in the wake of cancer and other “slow killers.”

The field of palliative care is one response to the changing profile of death in the twentieth century. It focuses on the prevention and relief of suffering through the meticulous management of symptoms from the early through the final stages of an illness; it attends closely to the emotional, spiritual, and practical needs of patients and those close to them. Other community, professional, and governmental responses include the development of hospice programs, bereavement support groups, and policies and

programs that encourage communication about people's goals and preferences as they approach death.

The twenty-first century will bring new realities as well as continuing problems and opportunities in care at the end of life. It will undoubtedly deliver improvements in what medical science can do to prevent and relieve distress for those approaching death, but demographic, economic, and other trends will strain systems that already find it difficult to deliver what clinical knowledge currently allows—and what compassion should grant.

The next century will see the final demographic consequences of the post-World War II baby boom. The oldest members of the baby boom generation will reach age 65 in the year 2011, and the youngest members will do so nearly 20 years later. The elderly will constitute a larger proportion of the population than today, and the absolute numbers of dying patients will be substantially higher. Although health care and social service providers have a long lead time compared with the educators and communities who had to scramble to provide schooling for the baby boom generation, the difficulties that policymakers are already having with Social Security and Medicare do not bode well for the nation's ability to cope with the social, medical, economic, and other effects of an aging population.

Contrary to some popular thinking, however, the increase in overall personal health care spending is not explained by disproportionate growth in costs for end-of-life care. The small percentage of people who die each year do account for a significant proportion of health care expenditures, but the share of spending accounted for by this group does not appear to have changed much since the 1970s. Overall, increased health care spending is primarily accounted for by population growth, general inflation in the economy, and additional medical care inflation. One reason for the attention to the cost of care at the end of life is that such care is, in considerable measure, funded through Medicare, Medicaid, veterans, and other public programs.

Pressures to control public and private health care costs will continue and, indeed, will likely intensify with consequent restructuring of how health care is organized, delivered, and financed. More older people with advanced disease will be served by different kinds of managed care organizations. If effective quality monitoring and improvement methods are in place, the strengths and limitations of these varied arrangements will become clearer as their experience with end-of-life care grows. Possible problem areas include contracting, payment, and review mechanisms that limit access to clinicians and care teams experienced in palliative care; patient scheduling norms that limit time for careful patient-clinician communication; and marketing strategies that may discourage enrollment by seriously ill people.

CONCEPTS AND PRINCIPLES

Notions of “good” and “bad” deaths are threaded throughout discussions about dying and death. These concepts are not fixed in meaning but rather are shaped by people’s experiences, spiritual beliefs, and culture and by changes in social mores, technology, and options for dying. Reflecting its members’ personal and professional experiences and philosophical perspectives, the study committee that developed this report proposed that people should be able to expect and achieve a decent or good death—*one that is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients’ and families’ wishes; and reasonably consistent with clinical, cultural, and ethical standards.* A bad death is characterized by needless suffering, disregard for patient or family wishes or values, and a sense among participants or observers that norms of decency have been offended.

The committee that prepared this report was guided by a set of working principles that reflect a combination of value judgments and empirical assumptions. Only the first of the following principles applies exclusively to care at the end of life.

Care for those approaching death is an integral and important part of health care. Everyone dies, and those at this stage of life deserve attention that is as thorough, active, and conscientious as that granted to those for whom cure or longer life is a realistic goal.

Care for those approaching death should involve and respect both patients and those close to them. Particularly for patients with a grim prognosis, clinicians need to consider patients in the context of their families and close relationships and to be sensitive to their culture, values, resources, and other characteristics.

Good care at the end of life depends on strong interpersonal skills, clinical knowledge, and technical proficiency, and it is informed by scientific evidence, values, and personal and professional experience. Clinical excellence is important because the frail condition of dying patients leaves little margin to rectify errors.

Changing individual behavior is difficult, but changing an organization or a culture is potentially a greater challenge—and often is a precondition for individual change. Deficiencies in care often reflect flaws in how the health care system functions, which means that correcting problems will require change at the system level.

The health care community has special responsibility for educating itself and others about the identification, management, and discussion of the last phase of fatal medical problems. Although health care professionals may not have a central presence in the lives of some people who are dying, many others draw heavily on physicians, nurses, social workers, and others

for care—and caring. Thus, health care professionals are inescapably responsible for educating themselves and helping to educate the broader community about good care for dying patients and their families.

More and better research is needed to increase our understanding of the clinical, cultural, organizational, and other practices or perspectives that can improve care for those approaching death. The committee began—and concluded—its deliberations with the view that the knowledge base for good end-of-life care has enormous gaps and is neglected in the design and funding of biomedical, clinical, psychosocial, and health services research.

CARING AT THE END OF LIFE: DIMENSIONS AND DEFICIENCIES

Care for most dying patients involves several basic elements: (1) understanding the physical, psychological, spiritual, and practical dimensions of caregiving; (2) identifying and communicating diagnosis and prognosis; (3) establishing goals and plans; and (4) fitting palliative and other care to these goals. In looking at current systems and practices, the committee found much that was good, including clinical, organizational, and ethical practices of palliative medicine that are implemented through hospices, interdisciplinary care teams in varied settings, innovative educational programs, and nascent outcomes measurement and quality monitoring and improvement strategies.

Notwithstanding these positive features, the committee concluded that very serious problems remain. It identified four broad deficiencies in the current care of people with life-threatening and incurable illnesses.

First and most fundamentally, too many people suffer needlessly at the end of life, both from errors of omission (when caregivers fail to provide palliative and supportive care known to be effective) and from errors of commission (when caregivers do what is known to be ineffective or even harmful). Studies have repeatedly indicated that a significant proportion of dying patients and patients with advanced disease experience serious pain, despite the availability of effective pharmacological and other options for relieving most pain. Other symptoms are less well studied, but the information available to the committee suggested a similar pattern of inadequate care. In perverse counterpoint to the problem of undertreatment, the aggressive use of ineffectual and intrusive interventions may prolong and even dishonor the period of dying. Some of this care is knowingly accepted; some is provided counter to patients' wishes; much is probably provided and accepted with little knowledge or consideration of its probable benefits and burdens.

Second, legal, organizational, and economic obstacles conspire to obstruct reliably excellent care at the end of life. Outdated and scientifically

flawed drug-prescribing laws, regulations, and interpretations by state medical boards continue to frustrate and intimidate physicians who wish to relieve their patients' pain. Addiction to opioids appropriately prescribed to relieve pain and other symptoms is virtually nonexistent, whereas underuse of these medications is a well-documented problem. Fragmented organizational structures often complicate coordination and continuity of care and impede the further development and application of palliative care strategies in patient care, professional education, and research. Medicare hospice benefits have made palliative services more available to a small segment of dying patients, but many more have illnesses that do not readily fit the traditional hospice model or government benefit requirements. Traditional financing mechanisms—including arrangements based on discounted fees—still provide incentives for the overuse of procedural services and the underprovision or poor coordination of the assessment, evaluation, management, and supportive services so important for people with serious chronic or progressive medical problems.

Third, the education and training of physicians and other health care professionals fail to provide them the attitudes, knowledge, and skills required to care well for the dying patient. Many deficiencies in practice stem from fundamental prior failures in professional education. Undergraduate, graduate, and continuing education do not sufficiently prepare health professionals to recognize the final phases of illnesses, understand and manage their own emotional reactions to death and dying, construct effective strategies for care, and communicate sensitively with patients and those close to them.

Fourth, current knowledge and understanding are insufficient to guide and support the consistent practice of evidence-based medicine at the end of life. Biomedical and clinical research have focused almost exclusively on the development of knowledge that contributes to the prevention, detection, or cure of disease and to the prolongation of life. Research on the end stages of diseases and the physiological bases of symptoms and symptom relief has had negligible support. Epidemiological and health services research has likewise not provided a strong base for understanding the degree to which people suffer symptoms (except, perhaps, cancer pain), experience death alone rather than in the company of those who care, comprehend diagnostic and prognostic information, and achieve a dying that is reasonably consistent with their preferences, palliative care principles, and community norms. Methods development is important to define and measure outcomes other than death (including patient and family perceptions) and to monitor and improve the quality of care for those approaching death.

More generally, this committee concluded that people in this country have not yet discovered how to talk realistically but comfortably about the end of life, nor have they learned how to value the period of dying as it is

now experienced by most people. Except for the occasional newspaper feature or television documentary, the reality of dying as most often experienced in the United States has been largely shunned by the news, information, and entertainment media as distasteful or uninteresting. One result is an unhelpful combination of fear, misinformation, and oversimplification that contributes to a public perception of misery as inescapable, pain as unavoidable, and public spending as misdirected for people approaching death.

RECOMMENDATIONS AND FUTURE DIRECTIONS

Seven recommendations address different decisionmakers and different deficiencies in care at the end of life. Each applies generally to people approaching death including those for whom death is imminent and those with serious, eventually fatal illnesses who may live for some time. Each is intended to contribute to the achievement of a compassionate care system that dying people and those close to them can rely on for respectful and effective care.

RECOMMENDATION 1: People with advanced, potentially fatal illnesses and those close to them should be able to expect and receive reliable, skillful, and supportive care. Educating people about care at the end of life is a critical responsibility of physicians, hospitals, hospices, support groups, public programs, and media. Most patients and families need information not only about diagnosis and prognosis but also about what support and what outcomes they should reasonably be able to expect. They should, for example, not be allowed to believe that pain is inevitable or that supportive care is incompatible with continuing efforts to diagnose and treat. They should learn—before their last few days of life—that supportive services are available from hospices and elsewhere in the community and that those involved in their care will help arrange such services. Patient and family expectations and understanding will be aided by advance care planning that considers needs and goals, identifies appropriate surrogate decisionmakers, and avoids narrow preoccupation with written directives. To these ends, health care organizations and other relevant parties should adopt policies regarding information, education, and assistance related to end-of-life decisions and services. For those who seek to build public understanding of dying as a part of life and to generate public demand for better supportive services, one model can be found in the perspectives, spirit, and strategies that have guided efforts to promote effective prenatal care and develop mother and family-oriented arrangements for childbirth.

RECOMMENDATION 2: Physicians, nurses, social workers, and other health professionals must commit themselves to improving care for dying patients and to using existing knowledge effectively to prevent and relieve pain and other symptoms. Patients often depend on health care professionals to manage the varying physical and psychological symptoms that accompany advanced illness. To meet their obligations to their patients, practitioners must hold themselves responsible for using existing knowledge and available interventions to assess, prevent, and relieve physical and emotional distress. When they identify organizational and other impediments to good practice, practitioners have the responsibility as individuals and members of larger groups to advocate for system change.

RECOMMENDATION 3: Because many problems in care stem from system problems, policymakers, consumer groups, and purchasers of health care should work with health care practitioners, organizations, and researchers to

- a. strengthen methods for measuring the quality of life and other outcomes of care for dying patients and those close to them;
- b. develop better tools and strategies for improving the quality of care and holding health care organizations accountable for care at the end of life;
- c. revise mechanisms for financing care so that they encourage rather than impede good end-of-life care and sustain rather than frustrate coordinated systems of excellent care; and
- d. reform drug prescription laws, burdensome regulations, and state medical board policies and practices that impede effective use of opioids to relieve pain and suffering.

Although individuals must act to improve care at the end of life, systems of care must be changed to support such action. Better information systems and tools for measuring outcomes and evaluating care are critical to the creation of effective and accountable systems of care and to the effective functioning of both internal and external systems of quality monitoring and improvement. Policymakers and purchasers need to consider both the long-recognized deficiencies of traditional fee-for-service arrangements and the less thoroughly understood limitations of alternatives, including various kinds of capitated and per case payment methods. Particularly in need of attention are payment mechanisms that fail to reward excellent care and create incentives for under- or overtreatment of those approaching death.

State medical societies, licensing boards, legislative committees, and other groups should cooperate to review drug prescribing laws, regulations,

board practices, and physician attitudes and practices to identify problem areas and then devise revisions in unduly burdensome statutes and regulations. Such regulatory change is not enough. It must be accompanied by education to increase knowledge and correct misperceptions about the appropriate medical use of opioids and about the biological mechanisms of opioid dependence, addiction, and pain management.

The committee identified characteristics of community care systems that would more effectively and reliably serve dying patients and their families. “Whole-community” approaches to end-of-life care would include a mix of programs, settings, personnel, procedures, and practices that extend beyond health care institutions and policies to involve entire communities. The goals would be to make effective palliative care available wherever and whenever the dying patient is cared for; help dying patients and their families to plan ahead and prepare for dying and death; and establish accountability for high quality care at the end of life. Box S.1 shows key features of a whole-community system for end-of-life care. A system with these components would reflect the understanding that there is not just one way to care for dying patients and that some flexibility is needed to respond to patients who do not comfortably fit the routines and standards that serve most patients well. Clearly, such a system represents an aspiration. The model implies cooperative effort involving public and private agencies on multiple levels—community, state, and national.

RECOMMENDATION 4: Educators and other health professionals should initiate changes in undergraduate, graduate, and continuing education to ensure that practitioners have relevant attitudes, knowledge, and skills to care well for dying patients. Dying is too important a part of life to be left to one or two required (but poorly attended) lectures, to be considered only in ethical and not clinical terms, or to be set aside on the grounds that medical educators are already swamped with competing demands for time and resources. Every health professional who deals directly with patients and families needs a basic grounding in competent and compassionate care for seriously ill and dying patients. For clinicians and others to be held truly accountable for their care of the dying, educators must be held accountable for what they teach and what they implicitly and explicitly honor as exemplary practice. Textbooks and other materials likewise need revision to reflect the reality that people die and that dying patients are not people for whom “nothing can be done.” Box S.2 outlines the fundamental elements of professional preparation for skillful, compassionate, and respectful care at the end of life.

RECOMMENDATION 5: Palliative care should become, if not a medical specialty, at least a defined area of expertise, education, and re-

BOX S.1
A Whole-Community Model for Care at the End of Life

Programs and settings of care suited to the needs and circumstances of different kinds of dying patients

- Home hospice programs
- Other palliative care arrangements for patients that do not fit the home care model
 - Day programs in hospitals and nursing homes, similar to those developed by geriatricians
 - “Step-down” arrangements including nursing homes that permit a less intensive and less expensive level of inpatient care when appropriate
 - Specialized inpatient palliative care beds for those with severe symptoms that cannot be well managed elsewhere
 - Respite programs to relieve families of patients with a long dying trajectory (e.g., those with Alzheimers Disease) that imposes major physical and emotional burdens on families

Personnel, protocols, and other mechanisms that support high quality, efficient, timely, and coordinated care

- Practical and valid assessment instruments and practice guidelines for patient evaluation and management that can be applied at both the individual and organizational level
 - Protocols for evaluating patient’s need for referral or transfer to other individual or organizational caregivers
 - Procedures for implementing patient transitions in ways that encourage continuity of care, respect patient and family preferences and comfort, and assure the transfer of necessary patient information
 - Consulting and crisis teams that extend and intensify efforts to allow patients to remain home despite difficult medical problems or crises
 - Ongoing professional education programs fitted to the varying needs of all clinicians who care for dying patients
 - Performance monitoring and improvement programs intended to identify and correct problems and to improve the average quality of care

Public and private policies, practices, and attitudes that help organizations and individuals

- Provider payment, coverage, and oversight policies that, at a minimum, do not restrict access to appropriate, timely palliative care and, as a goal, promote it
 - Support systems provided through workplaces, religious congregations, and other institutions to ease the emotional, financial, and practical burdens experienced by dying patients and their families
 - Public education programs that aim to improve general awareness, to encourage advance care planning, and to provide specific information at the time of need about resources for physical, emotional, spiritual, and practical caring at the end of life

BOX S.2 **Professional Preparation for End-of-Life Care**

Scientific and clinical knowledge and skills, including:

- Learning the biological mechanisms of dying from major illnesses and injuries
 - Understanding the pathophysiology of pain and other physical and emotional symptoms
 - Developing appropriate expertise and skill in the pharmacology of symptom management
 - Acquiring appropriate knowledge and skill in nonpharmacological symptom management
 - Learning the proper application and limits of life-prolonging interventions
 - Understanding tools for assessing patient symptoms, status, quality of life, and prognosis

Interpersonal skills and attitudes, including:

- Listening to patients, families, and other members of the health care team
- Conveying difficult news
- Understanding and managing patient and family responses to illness
- Providing information and guidance on prognosis and options
- Sharing decisionmaking and resolving conflicts
- Recognizing and understanding one's own feelings and anxieties about dying and death
 - Cultivating empathy
 - Developing sensitivity to religious, ethnic, and other differences

Ethical and professional principles, including:

- Doing good and avoiding harm
- Determining and respecting patient and family preferences
- Being alert to personal and organizational conflicts of interests
- Understanding societal/population interests and resources
- Weighing competing objectives or principles
- Acting as a role model of clinical proficiency, integrity, and compassion

Organizational skills, including:

- Developing and sustaining effective professional teamwork
- Understanding relevant rules and procedures set by health plans, hospitals, and others
 - Learning how to protect patients from harmful rules and procedures
 - Assessing and managing care options, settings, and transitions
 - Mobilizing supportive resources (e.g., palliative care consultants, community-based assistance)
 - Making effective use of existing financial resources and cultivating new funding sources

search. The objective is to create a cadre of palliative care experts whose numbers and talents are sufficient to (a) provide expert consultation and role models for colleagues, students, and other members of the health care team; (b) supply leadership for scientifically based and practically useful undergraduate, graduate, and continuing medical education; and (c) organize and conduct biomedical, clinical, behavioral, and health services research. More generally, palliative care must be redefined to include prevention as well as relief of symptoms.

RECOMMENDATION 6: The nation's research establishment should define and implement priorities for strengthening the knowledge base for end-of-life care. The research establishment includes the National Institutes of Health, other federal agencies (e.g., the Agency for Health Care Policy and Research, the Health Care Financing Administration, the National Center for Health Statistics), academic centers, researchers in many disciplines, pharmaceutical companies, and foundations supporting health research. One step is to take advantage of clinical trials by collecting more information on the quality of life of those who die while enrolled in experimental or treatment groups. A further step is to support more research on the physiological mechanisms and treatment of symptoms common during the end of life, including neuropsychiatric problems. Pain research appears to supply a good model for this enterprise to follow. To encourage change in the attitudes and understandings of the research establishment, the committee urges the National Institutes of Health and other public agencies to take the lead in organizing workshops, consensus conferences, and other projects that focus on what is and is not known about end-stage disease and symptom management and that propose an agenda for improvement. Demonstration projects to test new methods of financing and organizing care should be a priority for the Health Care Financing Administration. For the Agency for Health Care Policy and Research, the committee encourages support for the dissemination and replication of proven health care interventions and programs through clinical practice guidelines and other means.

RECOMMENDATION 7: A continuing public discussion is essential to develop a better understanding of the modern experience of dying, the options available to patients and families, and the obligations of communities to those approaching death. Individual conversations between practitioners and patients are important but cannot by themselves provide a more supportive environment for the attitudes and actions that make it possible for most people to die free from avoidable distress and to find the peace or meaning that is significant to them. Although efforts to reduce the entertainment and news media's emphasis on violent or sensational death and unrealistic medical rescue have not been notably successful, a modicum of

balance has recently been provided by thoughtful analyses, public forums, and other coverage of the clinical, emotional, and practical issues involved in end-of-life care. Regardless of how the current, highly publicized policy debate over physician-assisted suicide is resolved, the goal of improving care for those approaching death and the barriers to achieving that goal should not be allowed to fade from public consciousness. Much of the responsibility for keeping the public discussion going will rest not with the media but with public officials, professional organizations, religious leaders, and community groups.

The committee agreed that it would not take a position on the legality or morality of physician-assisted suicide. It does, however, believe that the issue should not take precedence over those reforms to the health care system that would improve care for dying patients.

CONCLUSION

The analyses, conclusions, and recommendations presented here are offered with optimism that people, individually and together, can act to “approach” death constructively and reduce suffering at the end of life. This report identifies steps that can be taken to improve care at the end of life and to create a solid foundation for maintaining such improvements through difficult times. It also highlights the reasons for believing that professionals, policymakers, and the public are becoming more aware of what can and should be done and are ready to embrace change. These reasons range from the examples of well-known men and women facing death with grace to the more intense focus on deficiencies in care that has been stimulated by the debate over assisted suicide. In sum, the timing appears right to press for a vigorous societal commitment to improve care at the end of life. That commitment would motivate and sustain individual and collective efforts to create a humane care system that people can trust to serve them well as they die.

APPROACHING DEATH

IMPROVING CARE
AT THE END OF LIFE

Committee on Care at the End of Life

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Division of Health Care Services

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This report has been reviewed by a group other than the authors according to procedures approved by a Report Review Committee consisting of members of the National Academy of Sciences, the National Academy of Engineering, and the Institute of Medicine.

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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The image adopted as a logotype by the Institute of Medicine is based on a relief carving from ancient Greece, now held by the Staatliche Museen in Berlin.

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Preface

After years of inattention, American society and American medicine are reexamining how we approach dying and death and how we care for people at the end of their lives. It may seem rather ironic that now, close to the year 2000, we are contemplating a reality as universal and certain as human mortality. Further, this is not the first time in this century that we have tried to rethink attitudes and practices as they relate to care at the end of life. In past years, critics and reformers have argued that medical technology has obscured humanistic compassion for dying people and those close to them. These voices have urged more humility about the reach of medicine and more compassion, empathy, and caring for people approaching death. Even though many important innovations, such as hospice programs and palliative medicine, have improved the care potentially available to dying patients, changes in attitudes and practices have been more limited than urged by reformers. Medical technology, meanwhile, has continued to advance, and the temptation remains great to ignore its limits and to evade the uncomfortable and emotionally challenging demands of facing these limits.

Dying, however, is part of life. This report argues that we can do much more to relieve suffering, respect personal dignity, and provide opportunities for people to find meaning in life's conclusion. We are heartened by the small but growing number of activities that are aimed at reaching these goals. Medical societies, health professions schools and certification organizations, charitable foundations, health systems, researchers, patient and community groups, and policymakers are all involved. When this Institute

of Medicine (IOM) study was first contemplated more than four years ago, very little of this work had been initiated.

This study itself arose in response to a request that the IOM conduct a project to develop guidelines for identifying and limiting futile treatments. After extensive consultations revealed many concerns that such a focus would not prove successful, the IOM undertook a six-month study of the feasibility and probable contribution of an IOM study on care at the end of life (Appendix A). Following two meetings and a workshop for which several background papers were prepared, the planning committee appointed to consider the question strongly endorsed a full-scale study that would both generally examine issues related to dying, decisionmaking, and appropriate care and selectively focus on several narrower topics. The group concluded that although much is being done to improve the care of critically ill and dying patients, many questions remain to be persuasively answered—or, for that matter, asked—about what constitutes appropriate care for different kinds of patients and how choices about care for dying patients can best be made and implemented.

In response, the IOM embarked on an extended effort to raise funds for a broad study that would make recommendations for improving care at the end of life. In late 1995, sufficient funding had been secured to permit the study to begin. To undertake the study, the IOM appointed a 12-member committee of experts in medical and nursing care for chronically and severely ill patients, ethics, quality of care, health policy, health services research, law, economics, social services, and related fields. The committee's broad tasks were to

- assess the state of knowledge about the clinical, behavioral, legal, economic, and other important aspects of care for patients with life-threatening medical problems;
- evaluate methods for measuring outcomes, predicting survival and functional status, determining patient and family preferences, and assessing quality of care;
- identify factors that impede or promote high-quality care for patients approaching death; and
- propose steps that policymakers, practitioners, and others could take to improve the organization, delivery, financing, assessment, and quality of care for those with terminal illnesses and to increase agreement on what constitutes appropriate care.

Between January 1996 and January 1997 the committee met five times. It also conducted two public meetings, one in Washington, D.C., and another in Irvine, California. Of the nearly 100 groups contacted, thirty-six groups presented statements at these meetings (see the meeting agendas in

Appendix B), and another 11 groups submitted written statements. The committee also met with researchers from the National Institutes of Health and other organizations. In addition to learning from the papers commissioned for the planning study, committee and staff reviewed literature (often quite sparse) on the issues identified in its charge. In addition, committee members participated in a workshop organized by the George Washington University Center to Improve Care of the Dying that began a process of developing a “toolkit” of quality and outcomes measures for end-of-life care. The committee also commissioned supplemental work for discussions of the epidemiology of dying and the cost of care at the end of life. This report, thus, reflects a wide-ranging effort to understand what we know about care at the end of life and what we have yet to learn.

The importance of this topic is undeniable. Unlike research about individual diseases, research about dying has the potential to touch every family and every individual in some way. Even those who die suddenly and unexpectedly can expect their survivors to benefit from a better understanding of grief and bereavement. The work of this committee and a growing number of others thus can bring great benefit. That biomedical science is making enormous strides also creates reasons for optimism about opportunities to better understand the pathophysiology of physical and emotional symptoms and to develop new approaches to preventing and ameliorating these symptoms. Increasing understanding of genetics, human biology, and longevity should not lead to dreams of near immortality but, rather, give us greater respect for the cycle of human life.

Medicine and public health should continue to help people live long, healthy lives. When medicine can no longer promise an extension of life, people should not fear that their dying will be marked by neglect, care inconsistent with their wishes, or preventable pain and other distress. They should be able to expect the health care system to assure reliable, effective, and humane caregiving. If we can fulfill that expectation, then public trust will be strengthened. The memorable words of Sir William Osler that we must “care always” will be renewed as a fundamental and abiding value.

Christine K. Cassel, M.D.
Chair

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Many individuals and groups assisted the study committee and staff in the development of this report. At the start, those who served on the feasibility study committee shaped the direction of the report in major ways, and the authors of several papers commissioned for that activity provided important insights and information. The members of that committee and the paper authors are listed in Appendix A (see also IOM, 1994). Two of the background papers are included in Appendices D and E.

Additional information and insights came from two public meetings, during which the committee heard from many organizations and individuals deeply involved with care of people with advanced progressive illnesses. Many participants made contributions beyond the public meetings to help us understand the difficult issues in end-of-life care. Appendix B includes the meeting agendas and participant lists and also cites the organizations that provided written testimony.

In addition, a workshop coordinated with Joan Teno, M.D. (then of the George Washington University's Center to Improve Care of the Dying, now at Brown University) was tremendously useful in understanding the array of potentially useful tools and instruments for measuring the quality of life and the quality of care for those approaching death. Information about the workshop is included in Appendix F.

Two very informative meetings were held with the following staff from the National Institutes of Health: Patricia Bryant, Ph.D., and Mitchell Max, M.D., of the National Institute of Dental Research; Bill Foster, M.D., Senior Staff Physician at NIH; Jack Killen, M.D., of the Division of AIDS in

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At the University of Virginia, Carlos Gomez, M.D., arranged a similarly useful visit that included opportunities to meet with community hospice, hospital, medical school, and other people involved in developing an inpatient hospice unit and in expanding the education of students and residents in end-of-life care. Among the many who were helpful to us were Victoria Todd, M.B.A., and Mary Jane Griffith, R.N., of the Hospice of the Piedmont; Elizabeth McGovern and John Herrmann from the Center for Hospice and Palliative Care; Carolyn Englehard, M.A.P.A., of the Virginia Health Policy Center; James Childress, Ph.D., and Marcia Finney, Ph.D.; and members of the Division of General Medicine including Drs. Daniel Becker, Munsey Wheby, Robert Carey, Margaret Reitmeyer, and Scott Robertson.

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Contents

SUMMARY	1
1 INTRODUCTION	14
The Need for Consensus and Action, 17	
Initiatives to Improve Care at the End of Life, 18	
Overview of Report, 21	
Guiding Principles, 22	
Concepts and Definitions, 23	
Conclusion, 32	
2 A PROFILE OF DEATH AND DYING IN AMERICA	33
When People Die: The Aging of America, 34	
Why People Die: Causes of Death, 37	
Where People Die: Death in Institutions and Residences, 39	
How People Die: Symptoms of Impending Death, 42	
Attitudes Toward Dying and Death, 44	
Conclusion, 46	
3 CARING AT THE END OF LIFE	50
Differences in Dying Pathways: Illustrative Cases, 52	
Determining and Communicating Diagnosis and Prognosis, 59	
Establishing Goals and Plans, 64	
Fitting Care to Goals and Circumstances, 72	
Conclusion, 86	

4	THE HEALTH CARE SYSTEM AND THE DYING PATIENT	87
	Characterizing Care Systems, 88	
	Illustrative Case Histories, 90	
	Settings for End-of-Life Care, 95	
	Coordinating Care Within and Across Settings, 107	
	Revisiting the Care System at the Community and National Levels, 116	
	Conclusion, 118	
	Addendum, 119	
5	ACCOUNTABILITY AND QUALITY IN END-OF-LIFE CARE	122
	Concepts of Accountability and Quality, 123	
	Evidence of Quality Problems in End-of-Life Care, 126	
	Dimensions of Quality in Care at the End of Life, 135	
	Measurement Instruments and Issues, 139	
	Guidelines for Clinical Practice, 149	
	Conclusion, 152	
6	FINANCIAL AND ECONOMIC ISSUES IN END-OF-LIFE CARE	154
	Who Pays for Care at the End of Life?, 155	
	What Is Spent for Care at the End of Life?, 156	
	Do Financing Mechanisms Impede Good End-of-Life Care?, 160	
	What About Proposals to Reduce the Cost of End-of-Life Care?, 173	
	Conclusion, 184	
	Addendum, 185	
7	LEGAL ISSUES	188
	Prescription Laws and Barriers to Pain Relief, 190	
	Informed Consent and Advance Care Planning, 198	
	Physician-Assisted Suicide, 203	
	Conclusion, 206	
8	EDUCATING CLINICIANS AND OTHER PROFESSIONALS	207
	Core Components of Professional Preparation for Care at the End of Life, 209	
	Physician Education, 210	
	Nursing, Social Work, and Other Professions, 227	
	Continuing Professional Education, 231	
	Conclusion, 232	

CONTENTS

xv

9	DIRECTIONS FOR RESEARCH TO IMPROVE CARE AT THE END OF LIFE	235
	A Symptom-Based Strategy for Biomedical Research, 236	
	Social, Behavioral, and Health Services Research, 244	
	Ethical Issues in Research on Dying Patients, 251	
	Research Leadership, 253	
	Conclusion, 258	
10	CONCLUSIONS AND RECOMMENDATIONS	259
	Today and Tomorrow, 260	
	Findings and Recommendations, 263	
	Concluding Thoughts, 271	
	REFERENCES	272
	APPENDIXES	
A	Institute of Medicine Feasibility Study on Care at the End of Life August 1993–February 1994	315
B	Institute of Medicine Committee on Care at the End of Life Public Meetings	321
C	Examples of Initiatives to Improve Care at the End of Life	327
D	Prognosis and Clinical Predictive Models for Critically Ill Patients	358
E	Cultural Diversity in Decisionmaking About Care at the End of Life	363
F	Measuring Care at the End of Life	383
G	Excerpts from <i>Medical Guidelines for Determining Prognosis in Selected NonCancer Diseases</i>	400
H	American Board of Internal Medicine Clinical Competence in End-of-Life Care	405
I	Examples of Medical Education Curricula	407
J	Committee Biographies	413
	INDEX	419

TABLES, FIGURES, AND BOXES

Tables

- 2.1 Infant Mortality Rates for the Ten Leading Causes of Infant Death, by Race: United States, January 1995, 38
- 2.2 Percentage Distribution for Locations Lived During the Last 90 Days of Life, According to Age and Sex (Survey of the Last Days of Life), 41
- 3.1 General Suggestions for Age-Appropriate Communication for Dying Children, 65
- 3.2 Adapting Advance Care Planning to Patient Circumstances: Possible Issues and Actions, 69
- 3.3 Primary Emphases of Care for Those with Different Goals Related to Life-Threatening Illness or Injury, 83
- 5.1 Symptoms Reported in 1969 and 1987 for Cancer and Other Deaths in Two English Studies, 130
- 5.2 Dimensions of Quality in Care of Dying Patients and Related Quality Strategies, 136
- 5.3 Categories of Patient/Family Outcome Measures for End-of-Life Care, 142
- 6.1 Medicare Payments Per Person-Year, According to Survival Status and Age, 1976 and 1988, 159
- 6.2 Medicare Enrollment and Payments, According to Survival Status, in 1976, 1980, 1985, and 1988, 160

Figures

- 1.1 Prototypical death trajectories, 29
- 2.1 Crude and age-adjusted death rates: United States, 1940–1990, 35
- 2.2 Life expectancy at birth by gender, 1900–1990, 36
- 2.3 Rates of consciousness and ability to communicate, 43
- 3.1 Alternative models of end-of-life care, 85
- 4.1 Interdisciplinary team for palliative home care, 110
- 5.1 Rates of severe symptoms in patients three days before death, as reported by family members, 129

Boxes

- 5.1 A Whole-Community Model for Care at the End of Life, 10
- 5.2 Professional Preparation for End-of-Life Care, 11
- 3.1 Communicating a Bad Prognosis to Patients and Families, 62
- 3.2 Examples of Communicating a Bad Prognosis, 63

- 3.3 Values Questionnaire Adapted from the Vermont Ethics Network, 67
- 3.4 Assessments Needed in Devising Palliative Care Plan, 74
- 3.5 Major Physical and Psychological Symptoms, 76
- 3.6 Practical Dimensions of Care for Patients and Families, 81
- 4.1 A Whole-Community Model for Care at the End of Life, 117
- 5.1 Guidelines for Improving the Quality of Treatment for Acute Pain and Cancer Pain, 127
- 5.2 Barriers to Cancer Pain Management, 133
- 5.3 Quality Domains Suggested by the American Geriatric Society, 140
- 5.4 Illustrative Examples of Items Proposed to Measure Individual Perceptions or Experiences, 144
- 5.5 Desirable Attributes of Outcomes Assessment Instruments Based on Criteria Developed by the Medical Outcomes Trust, 146
- 6.1 Implicit Age-Related Limitation of Care, 182
- 8.1 Professional Preparation for End-of-Life Care, 211
- 9.1 Limiting Factors in Research to Improve Care at the End of Life, 254

